There has been considerable discussion in England on the question of where clinical data should reside. On the one hand, the ‘point of care’ protagonists feel that clinical data (and clinical systems) should be focused on the patient, for use by the clinician at the point of care. On the other hand, those supporting registers and datasets feel that this is not adequate, and that standardised clinical data need to be brought together at a central point so that a number of clinicians and healthcare managers from a variety of healthcare sectors and providers can access them, for a number of differing purposes, such as epidemiology, quality improvement and audit, service planning, research and management.

The PHCSG briefing to Sir John Pattison (see page 179) demonstrates which side of the fence we prefer. Our view is that the purposes mentioned as justification for registers are vital to the running and development of the service. However, we believe it is possible to use data from within clinical records for those purposes without the additional step of creating separate registers or databases. It is, of course, essential that the clinical data used are of high quality, and that will require not only considerable training and education but also the availability of clinical computing systems appropriate to the task.

In the past few months in England the world has changed rapidly; we are now in a situation where The NHS Plan, which puts the patient’s needs and then the clinician’s at the centre of the strategy for delivering a health service, is becoming a reality.1 General practice has been using computers as a part of day-to-day care since 1978 and, since 1997–98, the penetration of computing into general practice is over 98%. Since the change in the GP terms of service in October 2000, there is good evidence that over 80% of GPs use their computers in every consultation.

### Registers

My definition of a register?

- An external database or spreadsheet, containing details of patients with a particular condition or set of conditions, set up for a particular purpose and maintained by some process involving multiple data extractions, questionnaires or discrete data collection exercises.

My problems with registers as defined above?

- Extra work for the data collection agencies and the clinician from whom the data are being acquired. This is fine if they are purely researchers but not if they are primarily clinicians.
- Inevitable inaccuracy as they will only be as up-to-date as the last data extraction, data laundry and entry into another system.

Do we have an alternative then? Let’s look at an example – diabetes. We run a continuous real-time audit at our practice. Each diabetic patient has embedded in his/her electronic record reminders for future care so we can assess where the patient is in our agreed care plan. The care is provided through a mixture of templates and decision support protocols. These automatically Read code the responses of the clinician.2 The design of the templates and protocols takes in the British Diabetic Association (now Diabetes UK), the Saint Vincent Declaration and emerging Diabetes National Service Framework needs and guidelines, as well as ten years of use in clinical practice, so that they do not slow us down or irritate us so much that we turn them off.3–5 Once a month we run a set of reports on the clinical system. These deliver a set of graphs and spreadsheets that identify the diabetics, show the care delivered, highlight where care is not being delivered and also show how many patients are due to attend in the coming months, allowing care planning, rota planning and holiday planning. We can choose to focus on a particular area (‘reduce mean cholesterol level’, ‘reduce diastolic blood pressure to under 80 in 90% of patients’, and so on), and be sure we know what this will do to the practice. We can also then produce many different sorts of reports, on both clinical and management aspects of care for patients with diabetes, without any fuss.

We can also do this for all NSF areas, cancer referral monitoring, cervical cytology, infant vaccinations,
travel vaccinations, our private pilot and racing driver medicals, and anything else we wish to set up in this way.

The best thing is that the extra work is practically zero. All we do as clinicians is make sure that the data are entered appropriately — this means paying attention to continuous education and training within the practice as well as significant event audit to ensure continued data quality. This is achieved through various reporting mechanisms from the clinical data. These must be available to all parties and can be either derived using the system’s own report generator or other data extraction tools. Such reporting allows the appropriate transfer of analysed data, anonymised if necessary, to an appropriately authorised agency or person. This functionality seems far in excess of what a register might do and of much greater benefit to patient care and clinician alike.

Datasets

So how about datasets? I used to spend a lot of time at the beginning of PRIMIS (April 2000) fielding requests for a ‘codeset’ or ‘dataset’ for ischaemic heart disease, diabetes, and so on. ‘Just tell me what to enter’ was a common request. This, to me, is the Collins phrasebook approach to a clinical terminology. We stood our ground and did not give out a set of codes for IHD that people could tack to the side of the monitor, next to the one for diabetes, the one for smears, the one for . . . Instead, we concentrated on education and training so that the structure, context and meaning (albeit imperfect) implicit within the Read codes and the clinical systems allowed the users to express their clinical work in a more eloquent and fluent fashion. Initially we were branded as ‘obstructive’ and ‘purist’. However, we rarely hear of people needing codesets or datasets any more.

Where you do need to be very careful is in the reporting of clinical data. We have developed sophisticated specifications for the groups of codes needed to report on clinical data and continue to develop more and more. We are also developing proxies and data quality measures that will enable the next turn of the ‘quality agenda wheel’ both at practice and PCT level.

Well, this is ‘just’ general practice — what about the rest of the service? As you are aware, there is an unseemly rush towards the new targets for 2005, with the danger that in an heroic attempt to spend £5 billion in bringing other parts of the service up to speed, we might throw the baby out with the bathwater! We must hope that the NHS will be well served by hearing some of the lessons that some of us in general practice have learned painfully over the last 20 years!

PHCSG 21st birthday

By the time you read this, the PHCSG will have celebrated its 21st birthday at the annual conference in Cambridge on 6–7 September. At the time of writing, we are deeply involved in organising the event. We have invited as many old members of the PHCSG as we can find to attend the event, and those members of the founding committee are also being invited to speak a few words to us at the conference dinner. We are sad to say that Dr Geoffrey Dove, a founder committee member who we had hoped would be a shining light at that event, died while helping someone who had had a car accident. We will be raising a glass to his memory, and hope to be able to announce a more tangible memorial in the near future.

REFERENCES

3 Diabetes UK. www.diabetes.org.uk
4 Saint Vincent Declaration. www.show.scot.nhs.uk/crag/topics/diabetes/vincent.htm
6 Primary Care Information Services (PRIMIS). www.primis.nhs.uk